

Highlights of the Annual Report to the Governor of Iowa

July 1, 2003 - June 30, 2004



Presented by the Iowa Council for Early ACCESS



Iowa's

Early Intervention System

Iowa's system for implementation of the Individuals with Disabilities Education Act, Part C

State of Iowa

Department of Education
Grimes State Office Building
Des Moines, Iowa 50319-0146

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The Honorable Thomas Vilsack
Governor
Iowa State Capitol
Des Moines, Iowa 50319



Dear Governor Vilsack:

On behalf of the Iowa Council for Early ACCESS, the State Interagency Coordinating Council created under Part C of the Individuals with Disabilities Education Act, I would like to present this summary of the Council's Annual Report for the period from July 1, 2003 through June 30, 2004. As you know, the Council advises and assists the Department of Education to develop and implement policies to improve Iowa's interagency system of early intervention services that help families to promote optimum development of their infants and toddlers with special needs.

This report highlights the results of activities of the Early ACCESS system in five areas:

1. Comprehensive Child Find
2. Family Centered Services
3. Early Intervention Services in Natural Environment
4. Early Childhood Transition
5. General Supervision and Infrastructure

These efforts were intended to help improve the system's ability to identify children in need of services, provide family-centered services to them in their natural environments, and facilitate the successful transition of toddlers out of Early ACCESS in ways that continue to support their development.

As your Council, however, we must take this opportunity to express our serious concern about the erosion of the resources needed to continue the progress summarized in this annual report. Given Iowa's changing demographics, the federal contribution to Iowa's Part C program is shrinking. At the same time, state funding for critical components of the Early ACCESS infrastructure (e.g. Child Health Specialty Clinics) is not keeping pace with growing needs. We greatly appreciate your advocacy for increased state appropriations for early childhood programs, including increased revenues to be targeted to Iowa's Medicaid program. Iowa's Early ACCESS system cannot be sustained without them.

We appreciate the opportunity to contribute to your Early Childhood Initiative by helping to build the capacity of Iowa's system to support infants and toddlers with special needs and their families. We look forward to continuing to work with you and all our state and community partners to achieve this goal.

Sincerely,

Robert Bacon, Chair
Iowa Council on Early ACCESS

HIGHLIGHTS OF 2004

The Iowa Council for Early ACCESS (ICEA) presents this report to the Governor and the people of Iowa about the efforts of the Early ACCESS system that occurred July 1, 2003 through June 30, 2004.

Vision: Every child, beginning at birth, will be healthy and successful.

Early ACCESS is part of Iowa's larger early care, health and education system that supports all young children. The Early ACCESS system is for children birth to age three who have developmental delays or specific conditions that are known to lead to developmental delay. Through Early ACCESS, infants and toddlers with developmental needs are identified early and receive the assistance they need to reach their potential and increase their readiness to learn.

INTERAGENCY COLLABORATION

Four state agencies work together through an interagency agreement to offer early intervention services to children and families:

- The Iowa Department of Education
- Iowa Department of Human Services
- Iowa Department of Public Health
- The University of Iowa Child Health Specialty Clinics

Together, these state agencies identify, coordinate, and provide needed services and resources to eligible children to help families. They also contribute resources and efforts to improve the system.

OTHER PARTNERS

Families, multiple regional and community agencies, as well as public and private providers also have a major role in making the system work.

LEAD AGENCY

The Department of Education is the designated Lead Agency with fiscal and legal responsibilities for the Early ACCESS system.

THE GRANTEES

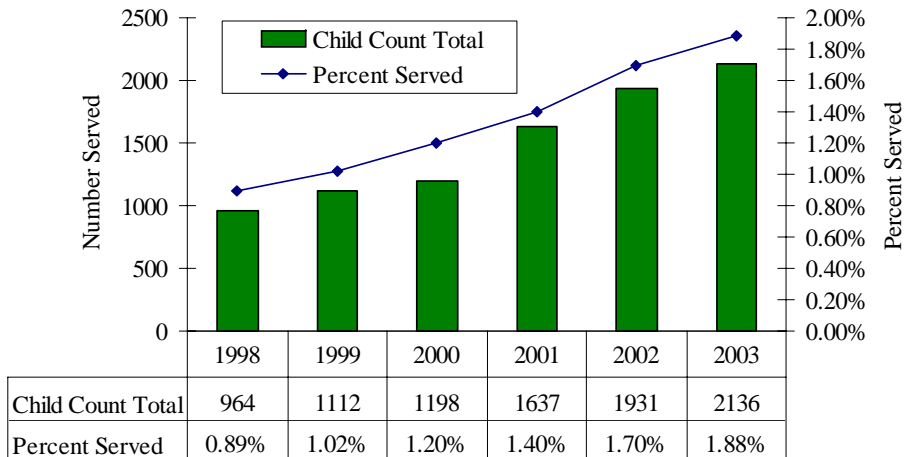
There are now twelve Area Education Agencies that have fiscal and legal responsibility for ensuring that the Early ACCESS system is carried out statewide. AEA Directors of Special Education serve as the grantee administrator. Grantees and the regional partners work together to identify all eligible children and assure needed early intervention services are provided.



To meet the child and family needs the system

- Works together in partnership with families
- Is family centered
- Identifies needs early
- Promotes early intervention
- Promotes services in settings that are most natural to families, and
- Respect cultural differences

The number and percent of infants served in Early ACCESS on the December, 2003.



Although progress has been steady over the last six years, less than 1% of children under age one are being referred to the Early ACCESS system.

Identifying developmental delay in infants under age 12 months is critical. In response, the Council has made this outcome a priority.

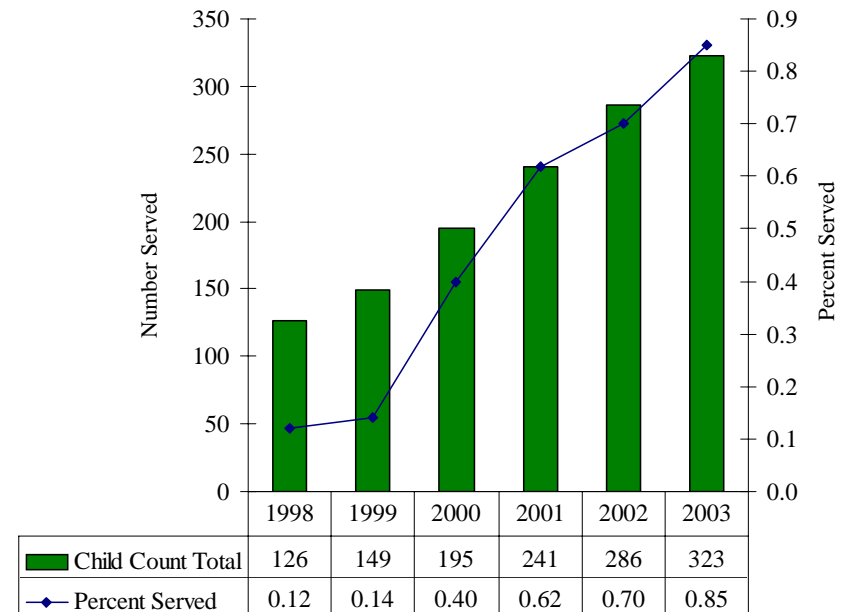
AREAS OF FOCUS IN 2004

- Comprehensive Child Find
- Early Intervention Services in the Natural Environment
- Family Centered Services
- Early Childhood Transition
- General Supervision and Infrastructure

COMPREHENSIVE CHILD FIND

Child Find means all the ways children with developmental delay, or conditions that may lead to developmental delay, are identified and referred to Early ACCESS. Early identification and referral is the key to a child's development and future success. For the last six years, there has been a consistent increase in the number and percentage of infants and toddlers receiving Early ACCESS services. This is because of the efforts made to improve *Child Find* activities.

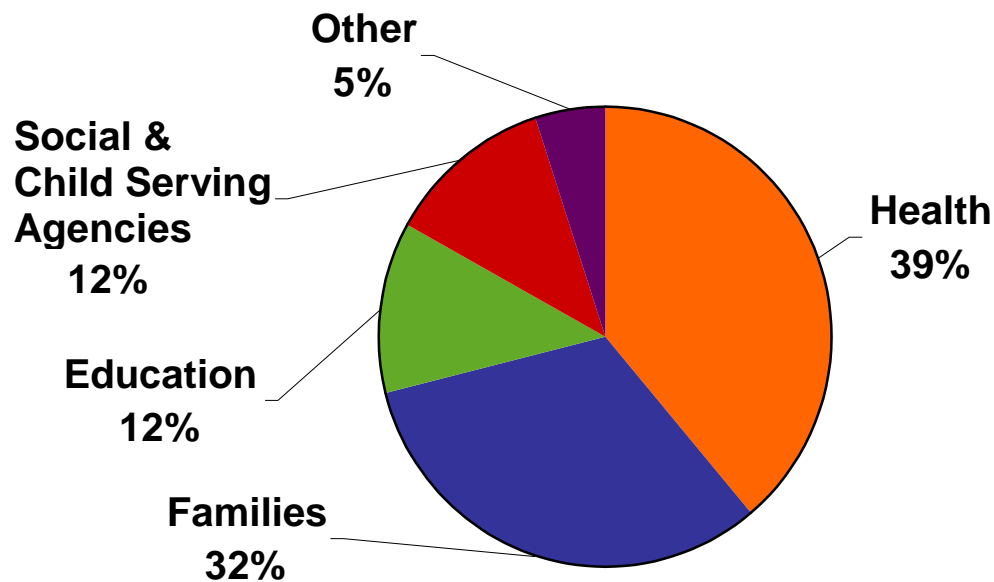
Number and Percent of Children Served in Early ACCESS from birth to age one.



Referrals

Families rely on many different professionals and word of mouth from other families and friends to find the help they need for their children. Families make up 32% of the initial contacts to Early ACCESS. Public awareness activities, along with improved communication from health professionals, have made a significant impact in the number of children who are receiving services. Now, 39% of all referrals come from health care professionals.

Percentage of Referrals by Referral Source



Activities for improving Child Find efforts:

- Made identification of children birth to age one a priority issue for the Council.
- Improved public awareness efforts.
- Designed COMPASS as the central point of entry that includes a toll free number and a “hotlink” directly to the local Early ACCESS number.
- Streamlined the referral system for physicians and other healthcare providers.
- Worked with DHS to develop procedures for referral through the Child Abuse Prevention and Treatment Act (CAPTA).
- Agreed upon a plan for interagency coordination of referrals through high-risk infant follow-up programs and Early Hearing, Detection and Intervention (EHDI).
- Developed a tracking system to monitor efforts.

Challenge

There is still work to be done. Despite the consistent increase in the number of children served, Iowa is still at 79% of the national average for the percent of infants and toddlers birth to age three served.



Percent of the infant and toddler population served compared to the national average

Iowa	1.78%
Nation	2.23%

EARLY INTERVENTION SERVICES IN NATURAL ENVIRONMENTS

Iowa makes an effort to provide services to children in places that are typical for a child who does not have a condition or developmental delay. This is referred to as a “natural environment.” If service in the natural environment is not possible, every effort is made to accommodate the child and family’s situation. Iowa children are primarily receiving care in their home or community.

Iowa consistently maintains a high percentage of services provided in natural environments and has exceeded the federal benchmark of 90% for three consecutive years.

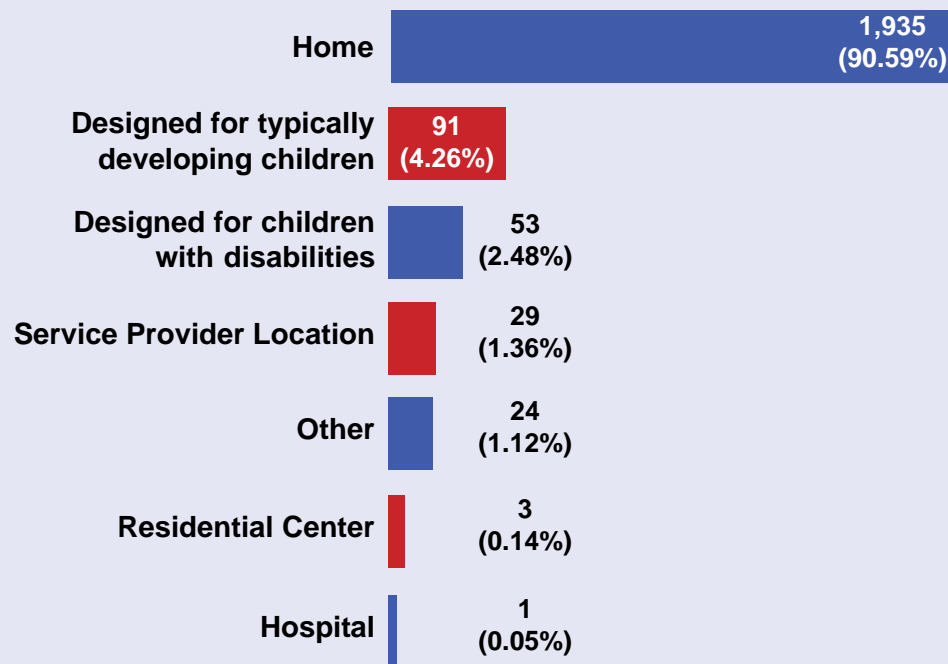
Activities for improving natural environments

- Provided training for local level Early ACCESS grantees regarding natural environments.
- Completed reviews at three regional grantee sites in Spring 2004 to monitor implementation of natural environments and provided corrective action, as needed, to improve services.

Challenge

1. To continue to maintain services in the natural environment for families as resources of partnering agencies are cut.
2. To further define natural environment as it pertains to services provided through partnering agencies.

Number and Percent of Settings Where Early Intervention Services Were Provided in 2004



“Early ACCESS is a program our family will always be thankful for! Early ACCESS provided us with the support we needed as soon as we brought our three little babies home from the hospital...physical therapy, speech testing, educational and age appropriate activities, and the understanding of what milestones our children should be reaching each month. Thankfully it all took place in our home. We will be forever grateful to the wonderful people that helped our children so much during their first 2 years of life.”

Maria & Russ Cooper
Pottawattamie County

FAMILY CENTERED SERVICES

Iowa has a strong history of partnering with families and considering family circumstances and needs for the development of a plan of services for each child. In addition, families play a key role in influencing policy.

Activities for improving family centered services

- Consistently increased the number of families who have received training to build leadership skills as well as to improve their ability to care for their child's special needs.
- Identified the set of skills or competencies that all Service Coordinators should have including outcome measures to evaluate those competencies. Competencies included skills for family-centered evaluation and development of the Individualized Family Service Plan (IFSP) that addressed child and family needs.
- Through a committee made up largely of parents, revised and distributed The Iowa Programs Providing and Financing Children's Care and Service guide to families receiving Early ACCESS services.

Challenge

1. To continue to maintain strong family leadership on committees of the Council.
2. To continue to recruit families who bring diverse racial and ethnic points of view to the Council.
3. To seek input from underserved families across the state about policies and procedures.

EARLY CHILDHOOD TRANSITION

Moving to preschool or other community services should be as smooth as possible for the child and family regardless of the

reason the child leaves the system. For that to happen, all Iowa children exiting Early ACCESS services should have a plan in place to support their move to preschool and other appropriate community services prior to leaving or by the time they are three years of age.

All Early ACCESS regional grantees have policies in place for how they plan to transition children to other services when they exit the system in accordance with federal regulations and administrative rules for Early ACCESS. These policies have been approved by, and are on file with the Department of Education.

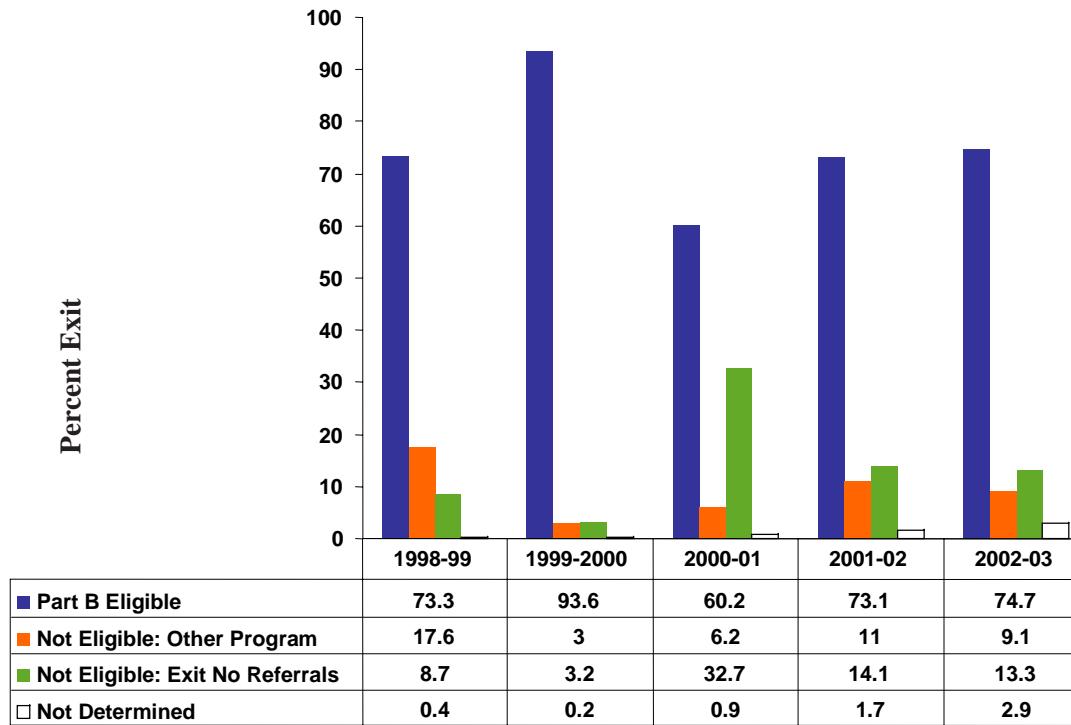
In 2004, 75% of children exiting Early ACCESS services were determined to be eligible for in-school (IDEA Part B) services with over 6% exiting to other communities.



"The Early ACCESS program has provided services to our twins ... since they came home from the hospital. They are now 2-years-old and both continue with speech-language pathology. The Early ACCESS Program has reassured us, as parents, that when they turn 3 we will all be prepared for the next step into the school system."

**Lori and John Scott,
Pottawattamie County, Iowa**

Number and percent of children who exited Early ACCESS services (Part C)



Not all children transition to school-age special education (Part B) services. An increasing percent of children, as shown in the graph, exit Early ACCESS before reaching age three because they improved their Early ACCESS skills and no longer require early intervention services. These families also need to know what supports are available to them as they leave the Early ACCESS system and what to do should they need help in the future.

Activities for improving transition services

- Four regional grantees surveyed parents about their transition experiences and used the comments to improve services.
- Technical assistance continued to grantees to help increase family involvement in transition planning activities.
- Continued to survey parents about their satisfaction when exiting the system because their child's skills improved.

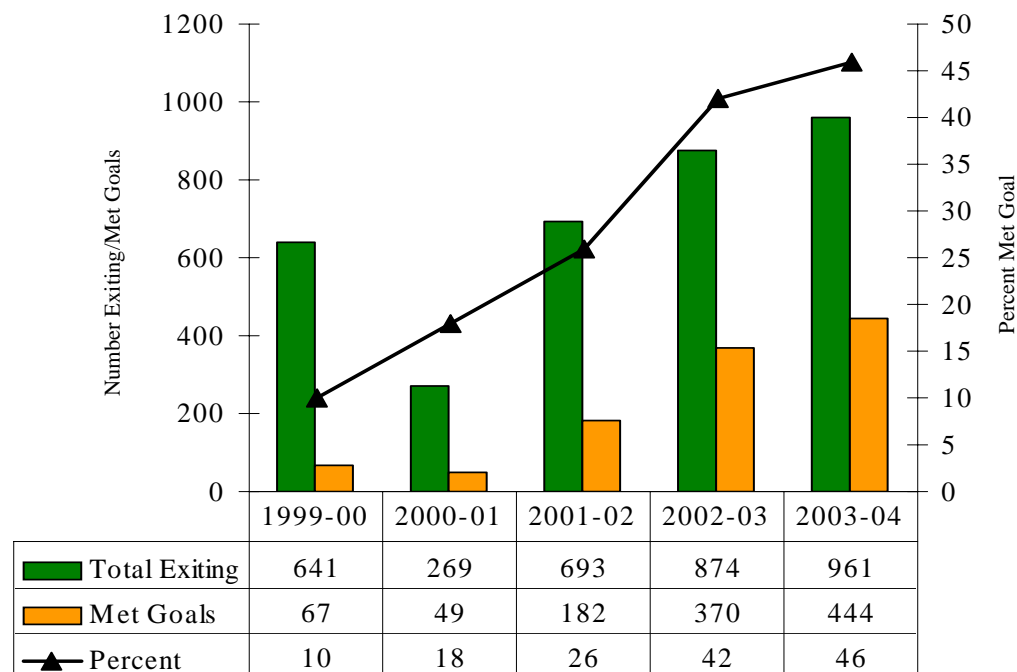
Challenge

1. To increase the number of families who have a plan when they leave Early ACCESS regardless of the reason.

“Early ACCESS provided the building blocks that Nathan needed to be able to be successful. Nathan is now attending kindergarten with his twin brother.”

Troy and Michelle McCarthy, Washington County

Number and percent of children exiting Early ACCESS because they met their goals



GENERAL SUPERVISION AND INFRASTRUCTURE

This year the Department of Education, with the advise and assistance role of the Council, completed activities of the State Improvement Plan approved by the Office of Special Education Programs (OSEP) in

December 2002. A final progress report of the plan submitted to OSEP July 22, 2004, described the status of the improvement strategies implemented and the corrective action steps taken in all areas of noncompliance identified by OSEP (<http://www.state.ia.us/earlyaccess/reports.html>).

Many of the successes this year were a result of the strengthening of the structures of the Early ACCESS system.

HIGHLIGHTS OF 2004 SYSTEM BUILDING ACTIVITIES INCLUDE

1. Major revision of the fifth edition of the Iowa Programs Providing and Financing Children's Care and Services. Parents use this directory to locate resources. It is also used by Service Coordinators to broaden their knowledge of services and support that are available. Seven thousand copies were distributed to all families in Early ACCESS, public libraries, Service Coordinators, advocacy groups and partnering agencies throughout the state. The guide is also available at the following website: <http://www.state.ia.us/earlyaccess/doc/iaprog02.pdf>.
2. Piloting a process to clarify roles and increase referrals from hospital neonatal intensive care units (NICUs) and high-risk infant follow-up programs that serve Iowa infants and toddlers.
3. Expansion of the role of COMPASS as central point of entry for public and private referral sources.
4. Agreement on interagency roles for CAPTA procedures.
5. Ensuring all agencies that become Medicaid providers of the Infant-Toddler Program met criteria for "Good Standing" in Early ACCESS.



6. Agreement on Early ACCESS system outcomes, indicators, competencies and quality standards for service coordination that formed the foundation of the Service Coordinator training program.
7. Training on transportation system needs, requirements and resources for all Regional Grantees in Fall 2003 culminating in transportation plans for each region.
8. Successful revision of the Individualized Family Service Plan (IFSP) and development of the IFSP review protocol, which addresses the underlying systemic causes for previous noncompliance.
9. Systematizing a cycle of data reporting and analysis designed to ensure data-based monitoring and continuous improvement for the Lead Agency and regional grantees.
10. Piloting the newly designed focused monitoring system for Early ACCESS regional grantees in June 2004.

CONTRIBUTIONS OF THE INTERAGENCY PARTNERS

Three state agencies work together with the Department of Education to provide services and supports for the Early ACCESS system. All four partners are active members of the Iowa Council for Early ACCESS and its Executive Committee. Each agency partner has made significant contributions to help improve or support the system of services for children and families in Iowa.

IOWA DEPARTMENT OF PUBLIC HEALTH (IDPH)

IDPH is responsible for Iowa's Maternal and Child Health and services for Title V of the Social Security Act of 1935. IDPH has a network of providers in every local community that partner with Early ACCESS grantees to provide local services. In addition, they contribute to planning, coordination and sharing of resources for the overall system of services.

"Children must be healthy before they can be ready to learn."

IDPH contributions to support Early ACCESS

1. The **Early Hearing Detection and Intervention (EDHI)** program, lead by IDPH, provides hearing screening to newborn infants statewide. The IDPH was instrumental in linking EDHI, Early ACCESS, and Iowa COMPASS to assure families receive access to follow up services for their child when the newborn hearing screening shows a need for more testing or care. A law mandating newborn hearing screening in Iowa went into effect January 1, 2004.
2. The **Assuring Better Child Health and Development (ABCD) II** is a grant from the Commonwealth Fund through the National Association for State Health Policy to DHS with coordination by IDPH. The goal of ABCD II is to improve the mental, social, and emotional development of young children birth through age three by working with Iowa's primary health care providers to increase early identification, referrals and treatment.
3. The **Covering Kids** project, funded by Robert Wood Johnson seeks to identify actual barriers to enrollment into child health insurance programs and implement system changes to remove barriers for Iowa's low income children. Because of the efforts of this program, more children have health insurance coverage through *hawk-i* or Medicaid for Early ACCESS services.
4. The **Early Childhood Comprehensive Systems** grant, directed by IDPH, brings together multiple partners statewide to promote a comprehensive, integrated, early care, health, and education system in Iowa including Early ACCESS. This effort is designed to pool resources and coordinate activities to more efficiently and effectively provide services to children and families. Partners in this effort are:
 - Community Empowerment
 - Department of Public Health
 - Department of Education
 - Department of Human Services
 - Department of Human Rights
 - Department of Economic Development

CHILD HEALTH SPECIALTY CLINICS (CHSC)

Child Health Specialty Clinics is Iowa's Title V Program for children with special health care needs. CHSC is a public health program authorized by Title V of the Social Security Act of 1935. CHSC provides direct health care services, care coordination services, and help to build high quality service systems for Iowa's children and families.

CHSC has an important role in Iowa's vision for all children to be healthy and ready to learn. Children with Special Health Care Needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services beyond that required by children generally (Maternal and Child Health, 1995).

CHSC contributions to support Early ACCESS

1. The **Iowa Medical Home Initiative (IMHI)** identifies children with special health care needs within primary care practices, provides children and families care coordination to link them to needed community services, and works to help develop meaningful involvement of families as partners in the care of their children.
2. The **Birth to Five Program** significantly contributes to the goal of building a statewide comprehensive early childhood system for Iowa's youngest citizens. A strong quality of CHSC's Birth to Five Program is its ability to offer screening, assessment, diagnosis, and referral for needed services.

Medical Home Common Elements

Care that is:

1. Accessible
2. Comprehensive
3. Coordinated
4. Culturally effective
5. Family-centered
6. Continuous
7. Compassionate

Family support and education accompanies the clinical and care coordination services. The Birth to Five Program is particularly useful to track and monitor children at-risk of developmental delay, but who are not eligible for Early ACCESS services.

3. CHSC is aware of the difficult contemporary problems facing Iowa's young children and has dedicated planning and clinical resources to understand the problems and be part of the solutions.

DEPARTMENT OF HUMAN SERVICES (DHS)

The Department of Human Services provides many services for children who are eligible for Early ACCESS that require coordination of resources including child care, mental health, Medicaid, waivers, and child abuse and protection services.

Department of Human Services contributions to support Early ACCESS

1. The **Home and Community Based Waivers** provides payment for services to eligible children in the Early ACCESS system. Of the 184 children under age three served by this program, 144 or 78% receive Early ACCESS services.
2. The **DHS foster care** system refers children under age three to Early ACCESS when they enter the system to determine if there is a concern about the child's development. One hundred children under age three are projected to be in foster care next year with an average stay of 10 months per child.
3. DHS worked with the Early ACCESS Council and the Department of Education to identify how to implement the changes in the **Child Abuse Prevention and Treatment Act (CAPTA)**. DHS predicts this change could potentially increase the number of children who will be referred to Early ACCESS in FY2005 by nearly 4000.
4. The **Infant and Toddler Medicaid Program** expansion improved funding for Early ACCESS services for Medicaid children.

STATE INTERAGENCY COUNCIL

The Iowa Council for Early ACCESS (ICEA) is Iowa's state interagency coordinating council for Early ACCESS. Twenty eight members appointed by the Governor advise and assist the Lead Agency, the Iowa Department of Education, about Iowa's Early ACCESS system. The Executive Committee guides the activities of the Council and sets the agenda.

Council meetings are held in the Des Moines area and are open to the public.

Meetings are the third Friday of...

September, November, January, March, and May

For more information and meeting agendas contact 515/281-3021.

COUNCIL ACTIVITIES

This year the Council focused its efforts on two priority areas:

1. Early identification birth to age one; and
2. Financing the Iowa Early ACCESS system.

Early Identification Committee

The Council was concerned that less than 1% of children under age one were being referred to the Early ACCESS system. Because early intervention is the difference that helps infants and toddlers with disabilities succeed, the Council believes it is imperative that infants be identified early and that intervention begins as early as possible in the child's life. In response, an Early Identification committee was established to seek ways to increase the number of children birth to age one who are referred to Early ACCESS services.

The committee advised the Department of Education regarding communication with families, providers and communities about early identification of children; training for Service Coordinators; and changes in referral processes. In addition the committee assisted with the development of a new brochure for families about Early ACCESS.

Resource Committee

The Resource committee was convened to identify sources of fiscal and other supports for Early ACCESS services in the state and to coordinate state resources of the interagency partners. It soon became apparent that there was a serious erosion of available resources needed to sustain services at current levels and to continue to improve the system.

The committee recommended that Early ACCESS Council members and staff participate in Mental Health/Mental Retardation/Developmental Disabilities/ Brain Injury (MH/MR/DD/BI) Commission Children's system redesign and that the Lead Agency pursue state dollars to support the Early ACCESS system. They also suggested exploring private insurance as a means of payment for services, recommended strategies to overcome barriers to health care participation in Early ACCESS and suggested possible changes to the Infant & Toddler Medicaid program requirements.

The Council continued efforts to:

1. Advise and assist the Lead Agency regarding new procedures and guidelines for the early intervention system.
2. Advocate for state and federal policies that improve services to children and families including:
 - changes related to CAPTA;
 - changes in policy guidelines from the Centers for Medicare and Medicaid Services (CMS) to allow reimbursement for Early ACCESS services for education-based providers.

3. Improve Council structures and functions.
4. Build leadership skills of Council members.
5. Build diversity of the Council membership.

Council future plans

The Council looks forward to continuing to build its capacity to carry out the role of advising and assisting the Lead Agency in the implementation of the statewide system for children and families in Iowa. Activities for next year include:

- Provide recommendations to Congress and OSERS for development of regulations for implementation of IDEA 2004;
- Develop the capacity of the Council to respond to public policy issues; and
- Continue to provide opportunities for parent leadership on the Council.

Challenges for the Early ACCESS System

The major challenge for 2005 will be to determine how to sustain system improvement with decreasing resources. As this year's report shows, system improvements in Early ACCESS have resulted in positive trends for children in Iowa. However, the Council is greatly alarmed by the erosion of resources that threatens the viability of our system. Our greatest challenge in the next year is to determine how to fund services for Iowa's families.

Other challenges

1. Increase the number of children served by the system birth to age one.
2. Improve communication with providers and referral sources.
3. Continue to develop interagency structures.
4. Implement cross agency service coordination.
5. Develop early learning outcomes in six areas for children birth to age three.
6. Improve transition from Early ACCESS to School based services.

Iowa Council for Early ACCESS Membership 2003-2004

PARENTS

Kyla Alba
Jennifer Gomez
Troy McCarthy
Bill Stumpf
Maureen Schletzbaum
Jan Mackey*
Andree Lawler*

SERVICE PROVIDERS

Royann, Mraz M.D., Pediatrician
Glenn Baughman, Mental Health
Debra Sixta M.D. , Family Physician
Greg Titus, Pediatric Nurse Practitioner
Glenn Grove,* Area Education Agency
Cathy Ryba, Part C Regional Coordinator
Renee Wallace, Child Health, Title V

STATE LEGISLATOR

Open

PERSONNEL PREPARATION

Robert Bacon,* Chairperson

HEAD START

Keri Burian, Early Headstart
Diane Halverson, Headstart

SIGNATORY AGENCIES

Lana Michelson,* Department of Education
Jane Borst,* Department of Public Health
Jeff Lobas,* Child Health Specialty Clinics
Jim Overland,* Department of Human Services

CHILD CARE

Sara Smoot

HEALTH INSURANCE

Shellie Goldman, Department of Human Services

TRIBAL COUNCIL REPRESENTATIVE

Georgette Sanache, Meskwaki Tribe

AT LARGE MEMBERS

Joel Yates
Kristyn Bell, Community Empowerment
Edward Loggins III, JETT
Georgia Woodward

*Members of the Early ACCESS Executive Committee

Early ACCESS Regional Grantees

AEA 1 Keystone, Elkader
AEA 4 Sioux Center
AEA 7 Area 267, Cedar Falls
AEA 8 Prairie Lakes, Fort Dodge
AEA 9 Mississippi Bend, Bettendorf
AEA 10 Grant Wood, Cedar Rapids
AEA 11 Heartland, Johnston
AEA 12 Western Hills, Sioux City
AEA 13 Loess Hills, Council Bluffs
AEA 14 Green Valley, Creston
AEA 15 Southern Prairie, Ottumwa
AEA 16 Great River, Burlington

State Staff

The state staff team consists of consultants representing families and the partnering agencies.

Julie Curry, Early ACCESS State Coordinator
Kay Leeper, Council Facilitator
Linnie Hanrahan, Secretary
Shelley Ackermann, Parent Consultant
Carrie Fitzgerald, Department of Public Health Consultant (until Feb 2004)
Erin Kongshaug, Department of Public Health Consultant (began Feb 2004)
Barbara Khal, Child Health Specialty Clinic Consultant
Marion Kresse, Department of Human Services Consultant
Lisa Sharp, Parent Consultant
Kathryn Wilson, Comprehensive System of Personnel Development Consultant
Dann Stevens, Medicaid Consultant
David Winans, Data Consultant

Acknowledgements

The Iowa Council for Early ACCESS wishes to thank the members of the Annual Report Committee for their efforts in preparing this report and the state staff for their work on the Annual Performance Report.

A special thanks for all the families, providers, and administrators who worked together to conduct and record their activities documented in this report.

Governor's Report Committee

Shanell Wagler, At Large – Community Empowerment, Chair
Kyla Alba, Parent
Dianne Halverson, Public Provider – Head Start
Robert Bacon, Chair, Iowa Council for Early ACCESS
Kay Leeper, Iowa Council for Early ACCESS Facilitator

Source of data: Office of Special Education, Annual Performance Report, 2003 - 2004.

Copies Available

Copies of this report and more in depth information can be found at <http://www.state.ia.us/earlyaccess/reports.html> or contact Early ACCESS at (515) 281-3021.

